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ABSTRACT

Title of Thesis: Health Perception and Symptom Severity in Bone Marrow Transplantation Patients

Christine S. Uebel, Master of Science, 1998

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Autologous Bone Marrow Transplantation (ABMT) management involves providing complex care for severely ill and immunocompromised patients. The ability to identify biodemographic, psychological and/or social factors which contribute to symptom development would be instrumental in the medical and nursing management of patients undergoing ABMT.

This study examined the relationship between health perception and symptom severity in post ABMT patients. A secondary analysis was performed on data from a convenience sample of 20 patients. Health perceptions were measured by Ware's Health Perception Questionnaire. The severity of pain, nausea, vomiting and depression were measured using questions from the European Organization Research and Treatment Quality of Life Questionnaire and Bush Late Complications of BMT Module. Approximately 65% of the patients in this study experienced pain, 30 % experienced nausea, and 35 % experienced depression post ABMT. Vomiting was not experienced by any of the patients. Pearson's product moment correlation was calculated and showed the relationship between the total scores for health perception and symptom severity was significant ($r = -.463, p = 0.05$), and revealed that the more severe the patient's symptoms were the lower their health perception was.

The results obtained indicate that pain, nausea, and depression associated with ABMT are problematic and negatively related to health perception. The results of this study may aid health care professionals in knowing what to expect regarding ABMT patients' ability to manage symptoms during their recovery.

Therefore, further research into the effects pain, nausea, vomiting, and depression have on health perception seems warranted in order to implement effective treatment regimens and facilitate recovery.

Health Perception and Symptom Severity in Bone Marrow Transplantation Patients

by
Christine Uebel

Thesis submitted to the Faculty of the Graduate School
of the University of Maryland in partial fulfillment
of the requirements for the degree of
Master of Science
1998

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Finally, “the views expressed in this thesis are those of the author and do not reflect the official policy or position of the United States Air Force, Department of Defense, or the United State’s Government.”

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Chapter 1

INTRODUCTION

Statement of the Problem

Bone marrow transplantation (BMT) “is a process by which nonfunctioning, deficient bone marrow or malignant cells are eliminated using high-dose chemotherapy and/or radiation followed by bone marrow or peripheral blood stem cell replacement or rescue in order to restore hematologic and immunologic function” (Shivnan, Shelton & Onners, 1996, p. 95).

Over the past 30 years BMT has evolved from an experimental procedure to an established and effective treatment. The earliest attempts at transplantation began in 1891 when Brown and Sequards administered marrow extract by mouth to patients with anemia and lymphadenoma (Buschel, 1989; Treleaven & Barrett, 1992). The success of these treatments was refuted. Billings (1894) and then Hamelton (1895) believed that the treatment’s positive effect was due to the mineral content in the bone marrow rather than to cell transfer (Treleaven & Barrett, 1992). As a result, clinical research in this area stopped until 1923.

“In 1923, Leake & Lecke used saline extracts of red bone marrow and spleen as haemopoietic stimulants, and observed some success in patients where other treatments had failed to resolve their anemia” (Trelevean & Barrett, 1992, p. 3). Later, in 1937, Schretzenmayr treated patients suffering from parasitic infections with intramuscular injections of fresh bone marrow with minimal success. These experiments led to further research and the first intravenous infusion of bone marrow was done in 1939 by

Osgood. Unfortunately, "this route of administration was subsequently ignored for many years" (Trelevean & Barrett, 1992, p. 3).

Not until after World War II did studies in bone marrow transplantation resume as researchers attempted to treat bone marrow failure resulting from irradiation. Research in the lab showed that animals given lethal doses of irradiation survived after parental infusions of bone marrow (Trelevean & Barrett, 1992). This led to the reinstitution of human bone marrow transplantation. In the late 1960s, following the discovery of tissue typing, a child with immune deficiency syndrome was successfully transplanted with marrow from a sibling (Buschel, 1989; Leukemia Society, 1995; Trelevean & Barrett, 1992). This led to the development of allogenic and autologous BMT therapy. Bone marrow transplantation can be either allogenic (which is the infusion of bone marrow harvested from another person) or autologous (when the patient is both the donor and recipient).

Autologous bone marrow transplant (ABMT) has become the most commonly used transplantation procedure in the treatment of immunological, hematological, genetic and oncological diseases (Campbell, 1996; Decker, 1995; Parkman, 1994). Prior to 1990 allogenic BMT was performed more often than ABMT. More than 400 teams worldwide perform an estimated 10,000 ABMTs annually (Campbell, 1996; Horowitz, 1995; Whedon, Stearns, & Mills, 1995). ABMT management involves providing complex care for severely ill and immunocompromised patients. ABMT recipients face a 10 to 20 % risk of death from infections and other related complications (Larson, 1995). Five to 10% of the recipients will experience graft versus host disease, 40% have cardiac

complications, and neurological sequelae are seen in 59 to 70% (Buchsel, Leum, & Randolph, 1996; Shivnan, Shelton, & Onners, 1996). Furthermore, mucositis, enteritis and skin desquamation are also prevalent with a reported incidence as high as 82 to 90%. These problems can cause severe nausea, vomiting, and pain (David & Musgrave, 1995; Gaston-Johansson, Franco, & Zimmerman, 1992; Larson, 1995; Lawrence, Gilbert, & Peters, 1996; McGuire, et al., 1993; Zerbe, Parkerson, Ortlieb, & Spitzer, 1992). Nausea, vomiting, and pain may be difficult to manage but rarely do they lead to catastrophic outcomes. However, they may result in anxiety, depression, prolonged hospital stays, and increased costs.

Studies examining autologous bone marrow transplantation are limited. The primary focus has been on long-term physical effects and quality of life (Andrykowski, 1994; Chao, et al., 1992; Prieto, et al., 1996; Whedon, Stearns, & Mills, 1995). Only recently have studies begun to address the role of biodemographic and psychosocial factors in the development and experience of symptoms associated with ABMT. In these studies researchers have attempted to identify mediating and/or causal factors in the development and exacerbation of physical symptoms. Age, diagnosis, locus of control, self efficacy, emotional distress (e.g. depression and anxiety), coping strategies and social support have been examined. Results have indicated that emotional distress is the most significant predictor of the physical condition of ABMT recipients, while locus of control, self efficacy and coping styles are also important factors (Gaston-Johansson, Franco, & Zimmerman, 1992; Prieto et al., 1996; Syrjala & Chapko, 1995). Futterman and colleagues (1991) retrospectively reviewed psychiatric consultations done on 42

BMT patients. They examined the consultations for seven characteristics: presence of psychiatric history, the quality of family and social support received, prior coping ability, present ability to cope with disease and treatment, quality of affect, mental status, and proneness to anticipatory problems. Each of these characteristics were then given an intensity rating which were calculated into an overall psychiatric score. They concluded that "less well-adjusted patients tend to regress more, especially during the periods of BMT conditioning regime (full body radiation plus high dose chemotherapy) and after BMT while awaiting engraftment. They are less tolerant of the physical pain associated with the BMT process, such as post radiation breakdown of oral tissues" (Futterman, Wellisch, Bond, & Carr, 1991, p. 185).

The ability to identify biodemographic, psychological and/or social factors which contribute to symptom development would be instrumental in the medical and nursing management of patients undergoing ABMT. Protocols and psychobehavioral interventions could be developed, targeting those factors which negatively impact patients during the ABMT process.

Purpose and Significance of the Study

The major purpose of this study was to identify whether an individual's health perceptions are related to symptom severity (i.e. nausea, vomiting, pain, and depression) during the ABMT process. A clearer understanding of selected characteristics of patients who develop severe nausea, vomiting, pain and depression during the transplantation process may facilitate identifying patients at risk pre-bone marrow removal.

The results of this study may aid health care professionals in knowing what to

expect regarding bone marrow transplantation patients' ability to manage symptoms during their recovery. This information may be beneficial in the development of appropriate protocols for symptom management, including support and teaching needed before and after transplantation.

Research Questions

1. What is the incidence of pain, nausea, vomiting, and depression in patients who have undergone ABMT?
2. Are these ABMT patient's perceptions of health related to the severity of these four symptoms?
3. Are the ages of these ABMT patients related to the severity of these four symptoms?
4. Are the diagnoses of these ABMT patients related to the severity of these four symptoms?
5. Are the ages of these ABMT patients related to their health perceptions?
6. Are the diagnoses of these ABMT patients related to their health perceptions?

Definition of Terms

The following terms are defined for use in this study.

Autologous bone marrow transplantation is the procedure used to treat hematological, oncological, immunological and genetic diseases. During this procedure nonfunctioning bone marrow and/or malignant cells are eliminated with high dose chemotherapy and/or radiation therapy. Patients then receive an infusion of their own bone marrow or peripheral blood stem cells in order to restore hematological and

immunological function (Shivnan, Shelton & Onners, 1996). Thus, the patient is both the bone marrow donor and the recipient.

Health perception is an individual's beliefs regarding six aspects of his/her health status as measured by current health, prior health, health outlook, health worry/concern, resistance/susceptibility, and rejection of the sick role. Current health is defined as the extent to which an individual identifies himself/herself as being healthy or ill. Prior health is an individual's perception of a favorable (healthy) or unfavorable (unhealthy) prior health history. Health outlook is the prediction of things to come. Health worry/concern is the extent of worry or concern an individual has about his/her state of health. Resistance/susceptibility refers to an individual's perception of his/her ability to resist illness. Rejection of the sick role is an individual's reaction to illness in terms of the extent to which he/she accepts or rejects the sick role (Ware, 1976).

Symptom is a noticeable change in a patient's condition indicative of physiological or psychological distress (i.e. nausea, vomiting, pain and depression) due to illness and/or treatment toxicity (Dorland's Illustrated Medical Dictionary, 1994).

Symptom severity is the intensity of a patient's symptoms and/or condition based on how distressing the patient perceives the symptom to be. The intensity of these symptoms can range from "not at all to extremely distressing" which may result in debilitation (Bush, Haberman, Donaldson, & Sullivan, 1995, p. 481).

Nausea is a subjective, conscious recognition of the desire to vomit which is mediated by the autonomic nervous system. It is manifested by wavelike sensations in the epigastric area and/or abdomen (Camp-Sorrell, 1997).

“Vomiting is a somatic process performed by the respiratory muscles causing forceful oral expulsion of gastric, duodenal or jejunal contents through the mouth” (Camp-Sorrell, 1997, p. 399). Vomiting occurs when the vomiting center in the medulla is activated by visceral, vagal and vestibular-cerebellar afferent pathways.

Pain is defined as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage” (International Association for the Study of Pain Subcommittee on Taxonomy, 1979, p. 249). Pain is a multidimensional phenomenon comprised of sensory, affective and cognitive components. Therefore, pain perception is the result of interactions involving psychological and emotional processes in addition to nociceptive and non-nociceptive impulses in ascending pathways in relation to descending inhibitory systems (Agency for Health Care Policy and Research, 1994).

Depression is a medical disorder that day after day affects thoughts, feelings, physical health and behavior (Agency for Health Care Policy and Research, 1993). It is a clinical syndrome characterized by psychological and physical symptoms (e.g. dysphoric mood, hopelessness, loss of self esteem, death wishes, restlessness, and changes in appetite) which is precipitated by guilt, loss, illness, pain and/or medication.

Limitations

The following limitations were identified:

1. The sample was selected from patients treated in one cancer center in Southern California, thus generalization is limited.

2. The small sample size increases the potential for the Type II errors in statistical conclusions.
3. The researcher did not collect these data. Therefore, the researcher is restricted to using the data originally collected and the forms/questionnaires used in the original study.

Summary

Autologous bone marrow transplantation is widely used to treat patients with immunological, hematological, genetic and oncological diseases. Post transplantation management involves the provision of complex care during the treatment of complications and associated symptoms.

Significant definitive psychological characteristics contributing to the development and management of symptoms in patients undergoing bone marrow transplantation have not been identified. Therefore, this study determined the relationship of health perception, disease and demographic features on symptom severity in an attempt to identify related factors that may be important.

Chapter 2

REVIEW OF LITERATURE

Bone marrow transplantation is being used with increased frequency for the treatment of a broad range of hemopoietic malignancies, neoplasms, and for certain nonmalignant conditions. It offers "long-term disease-free survival in more than half of some patients with previously fatal diseases" (Shivnan, Shelton & Onners, 1996, p. 95).

However, BMT is a complex and demanding procedure where psychosocial and physical concerns become paramount. Upon "receiving a diagnosis of cancer there is a universal response that life itself is threatened, and that life is now precarious and unpredictable" (Haberman, 1995, p. 25). In addition, individuals frequently experience the loss of personal control over their body and thoughts when undergoing cancer therapy (Bushkin, 1993). The immediacy of these threats may be even more salient for ABMT patients than for individuals receiving other treatments for cancer.

Haberman (1995), in his qualitative study, described the meaning of leukemia and personal control perceived by 23 adults undergoing BMT. For these individuals BMT was seen as their final hope for being cured. Their expectations were that "they would have little, if any control over the biomedical aspect of transplantation. Turning over control to the all powerful treatment protocol was a way to maximize the odds of success" (Haberman, 1995, p. 29). In this chapter the literature related to health perception and symptom severity (nausea, vomiting, pain and depression) in bone marrow transplantation patients is reviewed.

Health Perception

Only one study has been conducted on the effect an individual's health perceptions have on his/her recovery during BMT. Bush, Haberman, Donaldson and Sullivan (1995) conducted a descriptive study which examined the quality of life (QOL), psychological distress, demands of long term recovery, and health perceptions of 125 BMT survivors. Seven tests were administered (including the European Organization for Research and Treatment of Cancer QLQ - C30, Late Complications of BMT Module, Profile of Mood States and Ware's Health Perceptions Questionnaire) which included 271 different variables.

Results indicated that the majority of the BMT survivors were leading full and meaningful lives. They were no different than the individuals sampled from the general population in regards to being able to accurately assess their current health and health outlook. Yet, they "perceived their prior health as worse ($p < 0.001$, PV = 55.8%), felt more susceptible to illness ($p < 0.001$, PV = 11%), and were more worried about their health ($p < 0.001$, PV = 23.1%) than the general population" (Bush et al., 1995, p. 485). Moreover, none of the quality of life outcome measures varied significantly based on the recipients diagnosis or treatment regimen. "The only biodemographic variables that were significantly correlated with QOL outcomes were age at transplant and time since transplant. The greater the recipient's age at the time of transplant the lower the health worry/concerns ($r = 0.233$, $p < 0.005$, PV = 5.4%), and the more inclined survivors were to reject a sick role ($r = 0.26$, $p < 0.002$, PV = 6.8%)" (Bush, Haberman, Donaldson, & Sullivan, 1995, p. 486).

Nausea, Vomiting and Pain

Many studies have examined the relationship between mucositis, nausea, vomiting and pain in patients undergoing BMT (David & Musgrave, 1996; Gaston-Johansson, Franco, & Zimmerman, 1992; Larson, Viele, Coleman, Dibble, & Cebulski, 1993; Lawrence, Gilbert, & Peters, 1996; McGuire et al., 1993; Syrjala & Chapko, 1995; Zerbe et al., 1992). During the first month after BMT patients may experience severe mucositis and enteritis due to the conditioning regime and bone marrow infusion which in turn results in nausea, vomiting and diarrhea (David & Musgrave, 1996; Larson, 1995; Rodrigue, Boggs, Weiner, & Behen, 1993; Shivnan, Shelton, & Onners, 1996; Zerbe et al., 1992). The mucositis and enteritis may also cause severe pain. "The incidence of pain in BMT recipients has been reported to be as high as 82-100%" (David & Musgrave, 1996, p. 93). These symptoms have an insidious onset, generally escalate between seven and 14 days post BMT, and then subside 25 to 30 days after the BMT.

Gaston-Johansson, Franco, and Zimmerman (1992) examined pain and psychological distress two days prior to the ABMT and five, 10, and 20 days post ABMT in 17 patients. The subjects reported multifocal pain which they rated as being continuous during the first 20 days after the BMT. They described the pain as burning, sore, achy, nagging and annoying, and the most frequently occurring locations of pain were the oral cavity and abdomen. The pain scores correlated significantly with the individuals feeling anxious ($r = .44$, $p < 0.05$) and depressed ($r = .49$, $p < 0.05$). "Day 5 post ABMT appeared to be the most critical point, with patients reporting the most pain,

anxiety and depression" (Gaston-Johansson, Franco & Zimmerman, 1992, p. 47).

Zerbe et al. (1992) studied the patterns of oral mucositis and pain experienced by 24 hospitalized patients at a university center. The investigators used Eders, Berger and Peterson's Oral Assessment Guide to collect their data using retrospective chart reviews. Data analysis revealed a range of scores from eight to 24 (with eight being normal and 24 indicating severe abnormalities) for the prevalence of mucositis. The majority of the scores (89%) were greater than 16. Onset of the mucosal changes generally occurred between two days pre and post BMT, and peaked between five and 12 days post BMT. Pain was also experienced by a large majority of the individuals. Fifteen of the patients required a continuous infusion of morphine in order to control their pain.

McGuire et al. (1993) also assessed the incidence, onset, duration and severity of mucositis and pain in 47 cancer patients undergoing allogenic and autologous BMT. During this descriptive study, data were collected using the Short-Form McGill Pain Questionnaire (SF-MPQ) and an oral assessment examination tool. Mucositis occurred in 42 patients (89%), which began on day three post BMT, and resolved by day 12. The mucositis was most frequently seen in the soft palate, left buccal mucosa, tongue and floor of the mouth. Of the 42 patients with mucositis, 36 reported pain (86%). The pain was noted to begin on day four post BMT, and generally resolved by day 15. The pain was described as tender, aching, sharp, tiring and exhausting.

The relationship between the incidence of mucositis and pain, and the patient's age and type of transplant was also examined during this study. No significant associations were noted between these variables.

David and Musgrave (1996) also assessed the incidence, location, quality and intensity of pain experienced by nine post BMT patients. The MPQ and an Individual Pain Assessment Report found that 215 different pain episodes were experienced by the patients during the initial phase of their BMT. The most commonly reported sites of pain were the throat (28.8%), the face (23.7%), and the abdomen (12.09%). The pain was noted to have begun four days before the BMT and lasted on the average of 19 days post BMT with the highest incidence occurring on day six. The individuals described their pain as being sharp, burning, tender, dull, shooting, throbbing or splitting.

Syrjala and Chapko (1995) assessed 358 BMT patients for mucositis, mouth pain, and numerous psychological, social and biomedical variables (e.g. depression, anger, self efficacy, physical functioning, coping styles, support systems, gender and age) in an attempt to predict which individuals would experience greater or lesser pain during treatment.

Data analysis indicated that:

For the men in the study “the primary biomedical predictors of pain were mucositis ($r = 0.23, p \leq 0.01$) and age ($r = -0.29, p \leq 0.001$) during Days 0-6. BMT-distress pre-transplantation was also positively related to and the strongest psychological predictor of pain during Days 0-6 ($r = 0.26, p \leq 0.001$) and Days 17-24 ($r = 0.21, p \leq 0.01$), while Self-Efficacy was negatively related to and the strongest predictor of pain during Days 7-16 ($r = -0.29, p \leq 0.001$). For women, Self-Efficacy ($r = -0.27, p \leq 0.001$) was the strongest psychological predictor during Days 0-6, Avoidance ($r = 0.20, p \leq 0.05$) as a coping style is the strongest

predictor during Days 7-16, and Blames Self as a coping style is the strongest predictor of pain during Days 17-24 ($r = 0.24$, $p \leq 0.05$)” (Syrjala & Chapko, 1995, p. 75).

Additional research into the symptoms experienced by BMT recipients was also done by Larson et al. (1993). This study compared the perceptions of symptoms experienced by 30 BMT patients with perceptions of the 28 nurses caring for them. There was a significant difference between the nurses’ and the patients’ perceptions of symptom distress over time ($F = 6.413$, $p = 0.0011$). Patients perceived that loss of appetite, mucositis, pain and diarrhea were their most distressing symptoms. Nurses perceived that loss of appetite, pain, mucositis, fatigue and febrile episodes were the patient’s most distressing symptoms.

Anorexia, nausea, fatigue, bowel problems, pain and insomnia were also the most distressing symptoms experienced by ABMT patients in a study conducted by Lawrence, Gilbert and Peters (1996). In this study, 28 patients rated the symptoms they experienced on the Symptom Distress Scale on the day of admission to the hospital, the day of discharge, immediately after bone marrow reinfusion in the clinic, and before discharge from the clinic. Patient’s also recorded the number of retching and vomiting episodes experienced at home. Vomiting episodes ranged from one to 33 per patient and mild to intermittent nausea persisted for up to nine days post BMT despite antiemetic therapy. Most of the patients also reported mild occasional pain.

Depression

Depression and anxiety in relationship to BMT have been among the

psychological symptoms frequently studied with inconsistent results. Many researchers have reported that BMT patients generally undergo a depressive reaction accompanied by anxiety in response to their diagnosis and treatment (Colon, Callies, Popkin, & McGlave, 1991; Gaston-Johansson & Foxall, 1996; Gaston-Johansson, Franco, & Zimmerman, 1992; Grassi, Rosti, Albertazzi, & Marangolo, 1996; Jenkins, Linington, & Whittaker, 1991). In addition, the awareness of the death of other individuals undergoing BMT can be an additional stressor precipitating an individual's depression and anxiety.

Research has also indicated that the depressed mood state may be responsible for neuroendocrine and immunological changes. It may also prolong recovery by interfering with behaviors that facilitate recuperation by leading to decreased compliance with post-transplant requirements (e.g. medication administration and self-care) (Colon, Callies, Popkin, & McGlave, 1991).

Colon, Callies, Popkin, and McGlave (1991), studied symptoms of psychological distress in 100 BMT patients in a university hospital. On admission each patient was evaluated by the Adult Psychiatry Consultation Service. The investigators reviewed the consultation note and obtained data regarding psychiatric diagnosis, history of psychiatric illness, symptoms, and the patient's report of the emotional support they receive. Kaplan-Meier Survival Analysis was carried out with each of the variables. No direct relationship between the duration of survival and any psychiatric diagnosis was found. However, patients with depression were found to have a poorer rate of survival ($\chi^2 = 4.17$, $df = 1$, $p = 0.041$). The analysis also "indicated that depressed mood, perceived spouse/family support, and illness stage were independent of each other and

directly related to survival (chi square = 0.109, df = 2, p<.05). Patients with depressed mood, subsequent remissions, in relapse, or without extensive social support from family members appeared to be at an increased risk for untoward outcomes" (Colon, Callies, Popkin, & McGlave, 1991, p. 423).

Jenkins, Linington, and Whittaker (1991) found that 40% (13 of 25) of the BMT recipients in their study were depressed. No difference was found in the prevalence of depression between the individuals who had received an autologous BMT and those who had received an allogenic transplant.

Gaston-Johansson, Franco, & Zimmerman (1992) also reported the incidence of depression and anxiety in their descriptive study of 17 ABMT patients. Data were collected with the Pain-O-Meter (POM), State-Trait Anxiety Inventory (STAI), Beck's Depression Inventory (BDI), Multidimensional Health Locus of Control (MHLC) and the Coping Strategy Questionnaire (CSQ). Moderate to severe levels of anxiety along with mild to moderate levels of depression were found. Day five was the most critical period during which individuals experienced significantly more depression than on any other day ($p < 0.05$, $F [3, 59] = 2.81$).

Research done by Grassi, Rosti, Albertazzi, and Marangolo (1996) on the changes in psychological stress symptoms experienced by ABMT recipients also described the prevalence of anxiety and depression during therapy. Of the 49 patients in this study 30-50% reported moderate symptoms of anxiety and depression on admission. At the time of discharge these symptoms remained in 20-35% of the patients. There was also no association between the patient's diagnosis and their symptoms.

Gaston-Johansson and Foxall's study (1996), like the previous studies, found that ABMT patients experience depression and anxiety during the transplantation process. Individuals experienced the most depression two days before their BMT, and became less depressed over time. They were "significantly less depressed on day +20 than at baseline [$F(2,45) = 4.21, p < 0.05$]" (Gaston-Johansson & Foxall, 1996, p. 175). Moderate anxiety was also noted at baseline and again two days before the ABMT, followed by mild anxiety post-BMT. Anxiety and depression were correlated at baseline ($r = 0.62, p < 0.001$) and then again on the fifth day after the ABMT ($r = 0.70, p < 0.01$).

Summary

BMT is a complex and demanding procedure which is being used to treat a broad range of malignant diseases. During treatment a preparative regimen consisting of varying high doses of chemotherapy and/or radiation is given, followed by the bone marrow infusion. The agents used are highly toxic and affect both normal and abnormal cells. As a result, patients experience a variety of physical and psychological symptoms during BMT (e.g. anorexia, fatigue, bowel problems, mucositis, nausea, pain, and depression).

Research suggests the most commonly reported physiological symptoms are mucositis, nausea, vomiting and pain. Reported incidences have been as high as 82 to 100% in BMT recipients. In addition to the physiological symptoms, psychological symptoms are also prevalent. Researchers have reported that depression and anxiety are seen in 20 to 50% of bone marrow recipients.

Of these studies, only a few have reported findings regarding the relationship

between age, diagnosis, health perception and symptom severity. Hence, attention must be paid not only to the way BMT patients respond to their diagnosis and treatment, but also to how they perceive their condition. A previous study (Bush, Haberman, Donaldson & Sullivan, 1995) assessing health perceptions of BMT patients revealed that they were generally more worried about their health and felt more susceptible to illness than the general population.

Health perceptions such as these coupled with physiological and psychological symptoms could delay healing and recuperation. Therefore, further research identifying how age, diagnosis and health perceptions are related to BMT symptoms is needed in order to better manage physical and psychological symptoms, reduce complications and enhance personal control; thereby facilitating recovery.

Chapter 3

METHODOLOGY

Introduction

The sample, instrumentation, procedure and statistical analysis used in the study are discussed in this chapter. This study is a secondary analysis of an existing data set which examined the incidence of the symptoms of nausea, vomiting, pain and depression in patients who have undergone ABMT. The relationship between patients' perception of health and their symptom severity was also determined. The existing data are from research in which 45 ABMT patients were recruited to study the impact of implementing a critical pathway (22 patients were in the pre-implementation group, and 23 were in the post-implementation group). Of these 45, 10 expired (eight from the pre-implementation group and two from the post-implementation group). Two patients from the pre-implementation group and three from the post-implementation group declined participation in the study because of time constraints. Six patients were too sick to be interviewed (three from the pre-implementation group and three from the post-implementation group). In addition, four patients from the pre-implementation group could not be located.

Sample

A convenience, nonprobability sample of 20 adult post autologous bone marrow transplantation patients from one cancer center in Southern California were used for this study. All consenting patients from the original study who had an ABMT between May 30, 1990, and December 20, 1994, were included. The data on symptom severity and

health perceptions were collected over time (two to 50 months post ABMT).

Instrumentation

Four instruments were used in this study. Symptom occurrence and severity was determined by the European Organization for Research and Treatment Quality of Life Questionnaire (EORTC)(Appendix A) and the Bush Late Complications of BMT Module (Appendix B). Health Perception was determined by Ware's Health Perception Questionnaire (Appendix C). Demographic data were recorded on a data collection form developed by the principal investigator in the original study (Appendix D).

The European Organization for Research and Treatment Quality of Life Questionnaire (QLQ-C30) " incorporates nine multi-item scales: five functional scales (physical, role, cognitive, emotional, and social); three symptom scales (fatigue, pain, and nausea and vomiting); and a global health and quality-of-life scale" (Aaronson, et al., 1993, p. 366). Several single item measures assessed additional symptoms (i.e. dyspnea, appetite loss, sleep disturbance and diarrhea). Items are scaled either as Yes or No, or on a 4 point Likert scale. It was field tested in 13 countries on 305 patients to assess the quality of life of cancer patients participating in clinical trials. Reliability, assessed by Cronbach's alpha coefficient, ranged from .54 to .86 before treatment and from .52 to .89 during treatment. Three approaches were used to evaluate the questionnaire's validity. The nine scales were first correlated using Pearson's r. Repeated-measures Analysis of Variance (RM-ANOVA) was then used to evaluate the questionnaire's clinical validity. Finally, the questionnaire was administered twice, once prior to treatment and once during treatment, to evaluate the questionnaire's

responsiveness to health status changes. All of the inter-scale correlations were statistically significant ($p < .01$). The strongest correlations were observed between physical functioning, role functioning and fatigue scales with Pearson's r ranging from 0.54 to 0.63. In addition correlations were noted between fatigue, emotional and social functioning scales ($r > 0.40$). The global quality of life scale also correlated with the other scales (r ranged from -.26 to .55). Therefore, "the majority of the functional and symptom measures were able to distinguish clearly between patients differing in terms of performance status, weight loss and treatment toxicity" (Aaronson, et al., 1993, p. 365).

Five of the 30 questions from the EORTC which address the occurrence and severity of nausea, vomiting, pain and depression were used for this study (Table 1). Reliability for this study, assessed by Cronbach's alpha coefficient for the five items, was .685.

Bush's Late Complications of BMT Module contains 50 items which rate symptom occurrence and severity. The items are scaled identically to the EORTC using a 4 point Likert scale. "Content validity for the fifty items was derived from inservice discussions with Hutchinson Center staff and from the literature" (Bush, Haberman, Donaldson, & Sullivan, 1995, p. 481). No other discussion of reliability and validity was included. Seven of the 50 items which address the occurrence and severity of pain were used for this study (Table 2).

Ware's Health Perception Questionnaire provided information about an individual's beliefs regarding various aspects of his/her health status. Six different dimensions (or subscales) are measured with 32 items: Current Health, Prior Health,

Table 1

EORTC Symptom Questions

Questions	Rating Scale			
	Not at all	A little	Quite a bit	Very much
During the past week:				
1. Have you had pain?	1	2	3	4
2. Have you felt nauseated?	1	2	3	4
3. Have you vomited?	1	2	3	4
4. Did pain interfere with your daily activities?	1	2	3	4
5. Did you feel depressed?	1	2	3	4

Health Outlook, Health Worry/Concern, Resistance-Susceptibility, and Rejection of Sick Role (Appendix C). Items are scored on a 5 point Likert scale. Scores for each of the subscales are computed by summing the responses to the items used to measure each of the dimensions. The subscale scores are then summed into a total health perceptions score. Higher scores indicate a more positive perception of health. It has been field tested in five different locations in the United States with over 2,000 respondents and used in other research to provide information about an individual's beliefs regarding various aspects of his/her health status. Reliabilities of individual items ranged from

0.19 to 0.77 during test-retest correlations, with most of the correlations between 0.4 and 0.6. Test-retest reliabilities for the subscales ranged from 0.41 to 0.86, with internal consistency reliability coefficients ranging from 0.45 to 0.92 (Ware, 1981; 1976). “There is some evidence that the instruments are validly measuring what they intend to measure”(Ware, 1976, p. 159). This instrument was used to determine each patient’s total health perception score and subscale scores during this study. Reliability for this

Table 2

Bush BMT-Specific Module Symptom Questions

Questions	Rating Scale			
	Not at all	A little	Quite a bit	Very much
During the past two weeks:				
1. Have you experienced painful skin?	1	2	3	4
2. Have you experienced burning eyes?	1	2	3	4
3. Have you experienced mouth/throat soreness?	1	2	3	4
4. Have you experienced abdominal pain?	1	2	3	4
5. Have you experienced hip joint pain?	1	2	3	4
6. Have you experienced pain in other joints?	1	2	3	4
7. Have you experienced painful muscles?	1	2	3	4

study, assessed by Cronbach's alpha coefficient, was .85 for the total score.

Institutional Consent and Protection of Patient's Rights

The University of Southern California Institutional Review Board reviewed and approved the original research. Permission to use the data file was given by the Principal Investigator of the original study. No patient identifying information was given to this researcher.

Study Design

A correlational design was used to determine the incidence of symptoms of post ABMT patients, and to correlate patients' symptom occurrence and severity with their age, diagnosis and health perceptions.

Data Analysis

Data were analyzed using descriptive statistics to answer research question one. A correlational approach was used to answer research questions two, three and five. Research questions four and six were addressed using analysis of variance. The research questions were:

1. What is the incidence of pain, nausea, vomiting, and depression in patients who have undergone ABMT?"
2. Are these ABMT patients' perceptions of health related to the severity of these four symptoms?
3. Are the ages of these ABMT patients related to the severity of these four symptoms?

4. Are the diagnoses of these ABMT patients related to the severity of these four symptoms?
5. Are the ages of these ABMT patients related to their health perceptions?
6. Are the diagnoses of these ABMT patients related to their health perceptions?

Chapter 4

RESULTS

A description of the sample characteristics, as well as a description of the findings in relation to the six research questions are presented in this chapter.

The sample included 15 (75%) women and five (25%) men. Their ages ranged from 22 to 63 with a mean age at 45.85 years ($SD = 12.06$). The primary diagnoses were breast cancer (45%) and lymphoma (30%). The remaining diagnoses (25%) were other forms of cancer (Table 3).

Findings

Data analyzed included the ages, diagnosis, symptom severity scores and health perception scores of the ABMT patients. Results are presented by research question.

Question One

The first research question was: "What is the incidence of pain, nausea, vomiting, and depression in patients who have undergone ABMT?" Descriptive statistics were used to characterize the incidence and severity of pain, nausea, vomiting, and depression for each patient based on responses from the five questions selected from the EORTC QLQ, and the seven questions from Bush's Late Complication of BMT Module.

Pain in the past week as compared to nausea, vomiting, and depression was the most frequently occurring symptom (65%) (Table 4). Nine patients (45%) reported having had experienced "a little" pain, three patients (15%) reported having had "quite a bit" of pain and one individual reported having experienced "very much" pain. The most frequently reported sites of pain in the past two weeks were other joints (70% with a

Table 3

Sample Characteristics

Age categories	Frequency	Percentage
20-30	3	15
31-40	3	15
41-50	7	35
51-60	4	20
61-70	3	15
Diagnosis	Frequency	Percentage
Breast cancer	9	45
Lymphoma	6	30
Myeloma	2	10
Hodgkins	1	5
Leukemia	2	10

mean pain score of 2.05), muscles (70% with a mean pain score of 1.95), hip joints (50% with a mean pain score of 1.90), mouth/throat (35% with a mean pain score of 1.45), abdomen (35% with a mean pain score of 1.35), eyes (15% with a mean pain score of

1.20), and skin (10% with a mean pain score of 1.15). This pain interfered with the activities of seven patients.

Depression and nausea were also experienced by some patients post ABMT. Seven patients (35%) reported having felt depressed in the past two weeks. Of these seven, five rated themselves as being “a little bit” depressed while the other two rated their depression as “quite a bit.” Six patients (30%) reported having had experienced “a little bit” of nausea. It is interesting to note, that even though nausea was experienced, vomiting was not (Table 4).

Question Two

The second question was: “Are these ABMT patients’ perception of health related to the severity of these four symptoms?” In order to determine the relationship between health perception and symptom severity a Pearson’s product moment correlation coefficient (r) was calculated to describe the relationship between the symptom variables (pain, nausea, vomiting, depression) individual and total scores, and the health perception (total and subscale) scores. The total symptom score was negatively correlated with the health perception total score ($r = -.463, p < 0.05$). The health perception total score was also negatively correlated with having had pain in the past week ($r = -.539, p < 0.05$) and with having had interference with daily activities during the past week due to pain ($r = -.574, p < 0.01$). Of the six health perception subscales, “current health” correlated significantly both with having had pain in the past week ($r = -.571, p < 0.05$) and with having pain that interfered with daily activities during the past week ($r = -.756, p < 0.01$) (Table 5). These results indicate that those individuals

Table 4

Symptom Occurrence and Frequency

Symptoms	Mean	SD	Frequency (%)			
			1 Not at All	2 A Little	3 Quite A Bit	4 Very Much
Pain in the past week?	1.90	.85	35	45	15	5
Painful skin in the past two weeks?	1.15	.49	90	5	5	0
Painful muscles in the past two weeks?	1.95	.83	30	50	15	5
Abdominal pain in the past two weeks?	1.35	.49	65	35	0	0
Hip joint pain in the past two weeks?	1.90	1.12	50	25	10	15
Other joint pain in the past two weeks?	2.05	.89	30	40	25	5
Burning eyes in the past two weeks?	1.20	.52	85	10	5	0
Mouth/throat soreness in the past two weeks?	1.45	.76	65	30	0	5
Did pain interfere with your daily activities in the past week?	1.40	.60	65	30	5	0
Felt nauseated in the past week?	1.30	.47	70	30	0	0
Vomited in the past week?	1.00	.00	100	0	0	0
Felt depressed in the past week?	1.45	.69	65	25	10	0

who experienced pain and those whose pain interfered with their daily activities post

ABMT tended to have a negative perception of their current health.

Table 5

Correlations Between Symptom Severity and Health Perception Subscale Scores

Symptom	Total HPQ score	Current health	Prior health	Health outlook	Health worry	Rejection sick role	Resistance/susceptibility
Pain	-.539*	-.571*	-.188	-.284	.039	-.111	.052
Pain interfered with daily activities	-.686	.756**	-.196	.261	.198	-.354	.239
Nausea	-.157	-.208	-.151	-.249	.170	-.221	.157
Vomiting	.000	.000	.000	.000	.000	.000	.000
Depression	-.265	-.348	.100	-.397	.428	-.016	-.149
Total symptom score	-.463*	-.574*	-.113	-.163	-.024	.011	.124

Note: * Correlation is significant at the 0.05 level (2-tailed)

** Correlation is significant at the 0.01 level (2-tailed)

Question Three

The third research question was: "Are the ages of these ABMT patients related to the severity of these four symptoms?" Pearson's product moment correlation coefficient (r) was used to determine the relationship among age and the severity of pain, nausea, vomiting and depression experienced by the patients in this study (Table 6). Recall that

no patients reported experiencing vomiting.

No statistically significant relationship was found between age and the total symptom score, nausea or depression. However, there was a significant relationship between age and pain in general ($r = -.452$, $p < 0.05$). Older patients tended to report experiencing less pain post ABMT than younger patients in this study.

Table 6

Correlations Between Age and Symptom Severity

Symptoms	Age
Total symptom score	-.379
Pain in the past week	-.452*
Nausea in the past week	-.187
Vomiting in the past week	.000
Depression in the past week	-.087

Note: * Correlation is significant at the 0.05 level (2-tailed)

Question Four

The fourth research question was: "Are the diagnoses of these ABMT patients related to the symptom severity of these four symptoms?" In order to determine the relationship between diagnosis and symptom severity a One Way Analysis of Variance (ANOVA) was calculated to describe the relationship among the variables (diagnosis and

symptom severity scores) (Table 7). There was no significant relationship between the patients' diagnosis and their symptom severity. Due to the small sample size the analysis was repeated using a nonparametric test. The results are consistent using the Kruskal-Wallis Test (Table 8). Symptom severity does not differ by diagnoses.

Table 7

One Way Analysis of Variance of Symptom Severity by Diagnoses

		Sum of Squares	df	Mean Square	F	Sig.
Pain	Between Groups	3.100	2	1.550	2.463	.115
	Within Groups	10.700	17	.629		
	Total	13.800	19			
Nausea	Between Groups	1.000	2	.500	2.656	.099
	Within Groups	3.200	17	.188		
	Total	4.200	19			
Depression	Between Groups	.817	2	.408	.853	.443
	Within Groups	8.133	17	.478		
	Total	8.950	19			

Table 8

Kruskal-Wallis Test of the Relationship Between Symptom Severity and Diagnoses

	Diagnosis	N	Mean Rank	Chi-Square	df	Asymp. Sig.
Pain	Breast Ca	9	12.89	4.355	2	.113
	Lymphoma	6	8.25			
	Other Ca	5	8.90			
Nausea	Breast Ca	9	10.83	4.524	2	.104
	Lymphoma	6	7.50			
	Other Ca	5	13.50			
Depression	Breast Ca	9	12.39	2.357	2	.308
	Lymphoma	6	9.08			
	Other Ca	5	8.80			

Question Five

The fifth research question was: "Are the ages of these ABMT patients related to their health perceptions?" Once again a Pearson's product moment correlation coefficient (r) was calculated to describe the relationship among the variables (age, health perception total score, and the subscales: current health, health outlook, health worry/concern, prior health, rejection of the sick role, and resistance/susceptibility to illness). There was no significant relationship between the patient's age and the health perception total score. Of the six subscales, only prior health had a significant relationship with age ($r = .457$, $p < 0.05$) (Table 9). Older patients tended to perceive

their prior health as better than younger ABMT patients in this study.

Table 9

Correlations Between Age and Health Perceptions

Health perceptions	Age
Total health perceptions score	.068
Current health	-.108
Health outlook	.090
Health worry/concern	.036
Prior health	.457*
Rejection of the sick role	.351
Resistance/Susceptibility to illness	-.306

Note: * Correlation is significant at the 0.05 level (2-tailed)

Question Six

The final research question was: "Are the diagnoses of these ABMT patients related to their health perceptions?" One Way ANOVA was used to analyze the relationship between the variables (diagnosis, the health perception total score, and the subscales scores: current health, health outlook, prior health, health worry/concern, rejection of the sick role, and resistance/susceptibility to illness). There was no statistically significant relationship between these variables (Table 10). Due to the

small sample size the analysis was repeated using a nonparametric test. The results are consistent using the Kruskal-Wallis Test (Table 11).

Summary

The research questions were presented with their findings. Pain, nausea and depression were experienced by a third of the ABMT patients in this study. Younger patients experienced more pain than the older patients, and vomiting was not perceived as a problem.

This study also found a negative relationship between symptom severity and health perceptions. Lower symptom scores for pain, nausea, vomiting and depression were significantly correlated with higher perceptions of health ($r = -.463$, $p < 0.05$).

Analysis of the patients' age and their symptom severity also resulted in statistically significant correlations between abdominal pain ($r = -.463$, $p < 0.05$), pain in general ($r = -.452$, $p < 0.05$), and age. Older patients reported having less pain post ABMT than the younger patients in this study.

Patients' age, in relationship to their health perceptions, resulted in no statistically significant relationship; with the exception of the subscale: prior health ($r = .457$, $p < 0.05$). Thus, older patients in this study perceived their prior health as better than the younger patients.

Finally, no statistically significant relationship was found between the patients' symptom severity, their health perceptions, and their diagnoses.

Table 10

One Way ANOVA of Health Perceptions by Diagnoses

		Sum of Squares	df	Mean Square	F	Sig.
Current health	Between Groups	111.032	2	55.526	1.097	.358
	Within Groups	809.389	16	50.587		
	Total	920.421	18			
Health outlook	Between Groups	.526	2	.263	.263	.772
	Within Groups	16.000	16	1.000		
	Total	16.526	18			
Health worry/ concern	Between Groups	6.392	2	3.196	1.326	.293
	Within Groups	38.556	16	2.410		
	Total	44.947	18			
Prior health	Between Groups	1.725	2	.863	.183	.834
	Within Groups	75.222	16	2.410		
	Total	76.947	18			
Rejection of the sick role	Between Groups	30.892	2	15.446	1.900	.182
	Within Groups	130.056	16	8.128		
	Total	160.947	18			
Resistance/ Susceptibility to illness	Between Groups	1.308	2	.654	.097	.908
	Within Groups	107.639	16	6.727		
	Total	108.947	18			

Table 11

Kruskal-Wallis Test of the Relationship Between Health Perceptions and Diagnoses

	Diagnosis	N	Mean Rank	Chi-Square	df	Asymp. Sig.
Current health	Breast Ca	9	8.50	2.157	2	.340
	Lymphoma	6	12.75			
	Other Ca	4	9.25			
Health Outlook	Breast Ca	9	9.22	.409	2	.815
	Lymphoma	6	10.42			
	Other Ca	4	11.13			
Health Worry/ Concern	Breast Ca	9	12.00	2.288	2	.318
	Lymphoma	6	7.92			
	Other Ca	4	8.63			
Prior Health	Breast Ca	9	9.89	.182	2	.913
	Lymphoma	6	9.50			
	Other Ca	4	11.00			
Rejection of sick role	Breast Ca	9	10.56	1.953	2	.377
	Lymphoma	6	11.42			
	Other Ca	4	6.63			
Resistance/ Susceptibility	Breast Ca	9	9.56	.239	2	.887
	Lymphoma	6	10.92			
	Other Ca	4	9.63			
Total HPQ score	Breast Ca	9	9.17	2.278	2	.320
	Lymphoma	6	12.75			
	Other Ca	4	7.75			

Chapter 5

DISCUSSION, LIMITATIONS, CONCLUSIONS, IMPLICATIONS, AND RECOMMENDATIONS

Discussion

This section presents a summary and discussion of the findings in relationship to the research cited in the literature review. Each research question is addressed separately.

Question One

The first question was: "What is the incidence of pain, nausea, vomiting, and depression in patients who have undergone ABMT?" In this study pain was the most frequently occurring symptom (13 of the 20 patients reported pain) with a mean score of 1.90. Of these 13, nine patients reported having had experienced "a little" pain, three had "quite a bit" of pain, and one reporting having had severe pain. The most frequently reported sites of pain were: other joints (70% with a mean pain score of 2.05), the muscles (70% with a mean pain score of 1.95), and the hip joints (50% with a mean pain score of 1.90). Less frequently reported sites were the mouth/throat (35% with a mean pain score of 1.45), and the abdomen (35% with a mean pain score of 1.35). These percentages are similar to those reported by Gaston-Johansson, Franco, and Zimmerman (1992). They reported that the mean pain score for the 17 post ABMT patients in their study was 2.17. Their subjects also reported that their pain was multifocal in nature, with the most frequent locations being the oral cavity, the abdomen and then generalized body pain.

Larson, Veile, Coleman, Dibble and Cebulski (1993) and Lawrence, Gilbert, and Peters (1996) also found that pain was a distressing symptom for their patients. The mean pain score they reported was a "2" (1-5 Likert scale) with the throat, face and abdominal areas cited as the most frequent locations of pain in both of these studies.

In addition to describing the incidence and severity of pain, nausea, vomiting and depression were also examined. "A little bit" of nausea in the past week was the highest level experienced and it was reported by only six (30%) patients in this study. No one reported having vomited. These values are lower than those found by Lawrence, Gilbert, and Peters (1996) who reported that their 28 post BMT outpatients experienced "mild" nausea (median score of 2 on a 1-5 Likert scale) for up to nine days post BMT which was accompanied by vomiting episodes despite antiemetic therapy. The difference in results may reflect changes in practice, especially in the antiemetic regimen being used during the past five years, or the fact that the patients in this study were further out from their ABMT.

Depression in the past week was also experienced by a total of seven patients (35%) in this study. These results are similar to those found by Colon, Callies, Popkin, and McGlave (1991), Gaston-Johansson and Foxall (1996), Grassi, Rosti, Albertazzi, and Marangolo (1996), and Jenkins, Linington, and Whittaker (1996) who reported the incidence of depression on admission to be between 30 and 50%, which remained in 20 to 35% of the patients upon discharge.

Since pain, nausea, vomiting, and depression are not conducive to recovery and/or survival they remain a concern for clinicians. Thus, continued efforts to identify and

manage these symptoms is crucial.

Question Two

The second question was: "Are these ABMT patients' perception of health related to the severity of these four symptoms?" A statistically significant negative relationship ($r = -.463, p = 0.05$) was found between the total symptom severity score and the total health perception score. There were also statistically significant correlations between the health perception subscale "current health" and two of the symptoms: having had pain in the past week ($r = -.571, p = 0.05$) and having had pain interfere with daily activities during the past week ($r = -.756, p = 0.01$).

This was the second study which explored health perceptions in relationship to symptom severity in ABMT patients. Bush, Haberman, Donaldson, and Sullivan (1995) examined the quality of life, late medical complications, psychological distress, demands of long term recovery, and health perceptions of 125 ABMT survivors. They found pain (41%), emotional dysfunction (63.3%), joint/muscle discomfort (37.6%) and nausea/vomiting (12.9%) to be the symptoms with the highest reported incidence rates. Despite these symptoms, only six of the 125 respondents in their study rated their quality of life and health status as poor. These six survivors had experienced a much higher incidence rate (80 to 100%) and mean level of symptom severity. In addition, they showed "poorer function on the EORTC questionnaire, the BMT Module, POMS measures, and on the majority of the DBMT and WHPQ measures than the remaining 119 subjects in the sample" (Bush, Haberman, Donaldson, & Sullivan, 1995, p. 486).

Bush, Haberman, Donaldson, and Sullivan's results are not consistent with the results of this study. Their participants reported lower incidences of pain (41% versus 65%) and nausea (12.9% versus 30%), and a higher incidence of emotional dysfunction (63.3%) than the depression (35%) reported by the participants in this study. These differences may be attributed to the several different factors. The participants in the study by Bush and his colleagues were younger (mean of 28 years versus 45.8 years), only two percent had an ABMT, and 94% of their sample had leukemia and anemia while the sample in this study had primarily breast cancer and lymphoma.

Question Three

The third question was: "Are the ages of these ABMT patients related to the symptom severity of these four symptoms?" There was no significant relationship between age and the total symptom severity score, or between age and the scores for nausea, vomiting and depression. However, there was a significant relationship between age and pain in general ($r = -.452$, $p = 0.05$). These relationships indicate that the older patients reported experiencing less generalized pain post ABMT than did the younger patients. These results differed from prior research (Bush, Haberman, Donaldson, & Sullivan, 1995; McGuire, et al., 1993; Syrjala & Chapko, 1995). McGuire and colleagues reported that the incidence of pain experienced by the patients in their study "was not related to age, type of transplant, extensive pre treatment or busulfan exposure" (McGuire, et al., 1993, p. 1497).

Bush, Haberman, Donaldson, and Sullivan (1995) reported that age at time of transplant correlated significantly with quality of life outcomes. They found that older

patients experienced more fatigue and lower vigor/activity levels. "None of the other outcome measures varied significantly as a function of standard biodemographic, disease, or treatment variables" (Bush, Haberman, Donaldson, & Sullivan, 1995, p. 486).

As previously stated, Bush, Haberman, Donaldson, and Sullivan's study participants differed in several ways from the participants in this research which may account for the differences in the results. Their participants were younger (mean of 28 years versus 45.8 years), only two percent had an ABMT, and 94% of their sample had leukemia and anemia while the sample in this study had primarily breast cancer and lymphoma.

Syrjala and Chapko (1995) reported that age contributed significantly to the mouth pain experienced by the 196 men in their sample of 358 people ($r = -.029$, $p \leq 0.001$). The participants in Syrjala and Chapko's study also differed in several ways from the participants in this research which may account for the differences in the results. Their participants were also younger (mean age of 34 years old versus 45.8 years), and their sample had primarily leukemia while the sample in this study had primarily breast cancer and lymphoma.

Question Four

The fourth question was: "Are the diagnoses of these ABMT patients related to the symptom severity of these four symptoms?" This study, like the study by Bush, Haberman, Donaldson, and Sullivan (1995) found no relationship between diagnoses and symptom severity.

Question Five

The fifth question was: “Are the ages of these ABMT patients related to their health perceptions?” No significant relationship was found between the patients’ ages and their health perception total score. However, a significant correlation was found between age and the health perception subscale “prior health” ($r = .457$, $p = 0.05$) which indicates that the older patients’ perception of their prior health was more positive than the younger patients. These results are different from those reported in the literature. Bush, Haberman, Donaldson, and Sullivan (1995) found that patients older at the time of their BMT had lower scores on the health perception subscale “health worry/concern” ($r = 0.233$, $p < 0.005$), and were more inclined to “reject a sick role” ($r = 0.26$, $p < 0.002$).

However, as previously reported Bush, Haberman, Donaldson, and Sullivan’s study participants differed in several ways from the participants in this research which may account for the differences in the results. Their participants were younger (mean age of 28 years versus 45.8 years), only two percent had an ABMT, and 94% of their sample had leukemia and anemia while the sample in this study had primarily breast cancer and lymphoma.

Question Six

The final question was: “Are the diagnoses of these ABMT patients related to their health perceptions?” Once again, no significant relationship was found between these variables. Bush, Haberman, Donaldson, and Sullivan (1995) also found no difference between the type of disease, the type of transplant, or conditioning regimen

and health perception scores.

Limitations

The following limitation has been identified:

1. The results of this study have limited generalizability because of the sample size and the fact that data were collected in only one site.

Conclusions

The following conclusions concerning symptom severity, age, diagnoses, and health perceptions were derived as a result of this study:

1. The symptom severity scores for pain, nausea and depression of the ABMT patients in this study were: pain (with a mean score of 1.90) was experienced by 13 out of 20 patients (65%), a “little bit” of nausea (mean score of 1.30) was experienced by six patients (30%), and depression (with a mean score of 1.45) was experienced by seven patients (35%). These results are similar to those reported in the literature.
2. Vomiting was not experienced by any of the patients in this study. This finding is not commensurate with the results reported by other researchers.
3. Lower symptom severity scores are associated with higher perceptions of health.
4. The individuals in this study who experienced pain, and who had their daily activities disrupted due to pain, perceived their “current health” and over all health perceptions as worse than those reporting no pain.
5. There was no relationship between the patients’ age and the nausea, vomiting or depression they reported. However, there was a relationship between the patients’ age

and pain. Older patients experienced less pain than younger ones.

6. There was no relationship found between the patients' age and their perception of health except for the subscale "prior health". Older patients perceived their prior health as better than the younger patients.

7. There was no difference in the symptom severity or health perceptions of the patients in this study based on their diagnoses.

Implications

The results of this study indicate the importance of having health care professionals explore patient's symptom experiences and their health perceptions since the side effects of pain, nausea, and depression associated with ABMT are problematic many months after the ABMT. Uncontrolled pain, nausea, vomiting and/or depression may lead to poor nutritional intake, metabolic derangements, physical/psychological deterioration and negative health perceptions which may impact recovery and quality of life.

Nurses on ABMT units are in key positions to identify and provide treatment for the symptomology experienced by post ABMT patients, and to prepare patients for what they can expect after discharge. "Patient education that helps patients and their families to have realistic expectations about long-term outcomes may help to prevent such problems" (Baker, 1994, p. 89). Thus, various assessment strategies and pharmacological/nonpharmacological interventions such as discussing patient's perceptions/expectations of care needs, providing realistic information about ABMT, increasing the patient's control over symptom relief (e.g. patient controlled analgesia),

and teaching relaxation and coping strategies may be employed by nurses to help patients with the physiological and psychological distress associated with ABMT.

Recommendations for Further Research

Based on the findings of this study, the following recommendations are made for further research:

1. Replicate this study, using a larger sample size.
2. Study the relationship between symptom severity and health perceptions during the first 30 days following ABMT treatment rather than retrospectively with survivors.
3. Explore the relationship between symptom severity and health perceptions in a longitudinal study controlling the antiemetic and analgesic medication regimens in order to determine how symptoms and health perceptions change over time.

Appendix A

European Organization for Research and Treatment of Cancer

Quality of Life Questionnaire

Appendix A

EORTC QLQ-30

	No	Yes
1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2
2. Do you have any trouble taking a <u>long</u> walk?	1	2
3. Do you have any trouble taking a <u>short</u> walk outside of the house?	1	2
4. Do you have to stay in a bed or a chair for most of the day?	1	2
5. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2
6. Are you limited in any way in doing either your work or doing household jobs?	1	2
7. Are you completely unable to work at a job or to do household jobs?	1	2

During the past week:

	Not at All	A Little	Quite a Bit	Very Much
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8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Did you need to rest?	1	2	3	4
11. Have you had trouble sleeping?	1	2	3	4
12. Have you felt weak?	1	2	3	4
13. Have you lacked appetite?	1	2	3	4
14. Have you felt nauseated?	1	2	3	4
15. Have you vomited?	1	2	3	4
16. Have you been constipated?	1	2	3	4

During the past week:	Not at All	A Little	Quite a Bit	Very Much
17. Have you had diarrhea?	1	2	3	4
18. Were you tired?	1	2	3	4
19. Did pain interfere with your daily activities?	1	2	3	4
20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21. Did you feel tense?	1	2	3	4
22. Did you worry?	1	2	3	4
23. Did you feel irritable?	1	2	3	4
24. Did you feel depressed?	1	2	3	4
25. Have you had difficulty remembering things?	1	2	3	4
26. Has your physical condition or medical treatment interfered with your <u>family</u> life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your <u>social</u> activities?	1	2	3	4
28. Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you

29. How would you rate your overall physical condition during the past week?

1 2 3 4 5 6 7

Very poor

Excellent

30. How would you rate your overall quality of life during the past week?

1 2 3 4 5 6 7

Very poor

Excellent

Appendix B

Bush Late Complications of BMT Module

Appendix B

BMT-Specific Module
(Nigel Bush, PhD; c 1990)

Former bone marrow transplant patients sometimes report that they have the following symptoms. Please indicate the extent to which you have experienced these symptoms during the past 2 weeks.

During the past 2 weeks, to what extent have you experienced:

	<i>Not at all</i>	<i>A little bit</i>	<i>Quite a bit</i>	<i>Very Much</i>
(31) Skin problems				
(a) Rashes	1	2	3	4
(b) Dryness	1	2	3	4
(c) Sweating	1	2	3	4
(d) Painful skin	1	2	3	4
(e) Skin ulcers	1	2	3	4
(32) Hair Loss	1	2	3	4
(33) Nail Loss	1	2	3	4
(34) Eye problems				
(a) Dryness	1	2	3	4
(b) Grittiness	1	2	3	4
(c) Burning	1	2	3	4
(d) Blurring	1	2	3	4
(e) Sensitivity to light	1	2	3	4
(f) Cataracts	1	2	3	4

During the past 2 weeks, to what extent have you experienced:

	Not at all	A little bit	Quite a bit	Very Much
(35) Mouth/throat problems				
(a) Dryness	1	2	3	4
(b) Soreness	1	2	3	4
(c) Burning	1	2	3	4
(36) Teeth problems (dental caries, etc.)	1	2	3	4
(37) Abnormal sense of taste for food or drink	1	2	3	4
(38) Heartburn	1	2	3	4
(39) Abdominal pain	1	2	3	4
(40) Weight loss	1	2	3	4
(41) Sinusitis	1	2	3	4
(42) Runny nose	1	2	3	4
(43) Breathing Problems				
(a) Coughing	1	2	3	4
(b) Wheezing	1	2	3	4
(c) Bronchitis	1	2	3	4
(d) Asthma	1	2	3	4
(44) Painful joints				
(a) Hip joints	1	2	3	4
(b) Other joints	1	2	3	4
(45) Painful muscles	1	2	3	4
(46) Varicella zoster (VZV)	1	2	3	4
(47) Herpes Simplex	1	2	3	4

During the past 2 weeks, to what extent have you experienced:

		Not at all	A little bit	Quite a bit	Very Much
(48)	Cytomegalovirus (CMV)	1	2	3	4
(49)	Pneumonia	1	2	3	4
(50)	Measles	1	2	3	4
(51)	Chickenpox	1	2	3	4
(52)	Shingles	1	2	3	4
(53)	Chronic graft-versus-host disease (GVHD)	1	2	3	4
(54)	Minor symptoms or ailments? (common cold, flu, migraine, etc.)	1	2	3	4

Please describe

- (55) Compared with your appearance before your bone-marrow transplant, how satisfied are you with your appearance now?

		Not at all	A little bit	Quite a bit	Very Much
(56)	Have you been satisfied with your own sexual appeal?	1	2	3	4
(57)	Have you been satisfied with your ability to share warmth and intimacy?	1	2	3	4
(58)	Have you been interested in sexual thoughts or feelings?	1	2	3	4
(59)	Do you have any physical problems that reduce your satisfaction with sex and intimacy		YES	NO	

Please describe (remember that your answers will be treated with the strictest confidence).

During the past 2 weeks:	Not at all	A little bit	Quite a bit	Very Much
(60) Have you been worried by fear of infection?	1	2	3	4
(61) Have you been worried by thoughts about relapse or dying?	1	2	3	4
(62) Have you had difficulty in maintaining your attention and train of thought?	1	2	3	4
(63) Have you had difficulty in reasoning and thinking clearly?	1	2	3	4
(64) Are there any other things that have affected the quality of your life over the past 2 weeks?				

- (65) Has the quality of your life over the past 2 weeks been typical of the past 5 or 6 months, or has it been unusual? If the past 2 weeks have been unusual, please describe how, in more detail.

Please check to make sure that you have answered all of the questions.

Please use the space below for any additional comments you might have:

Appendix C

Ware's Health Perception Questionnaire

Appendix C
HEALTH PERCEPTIONS QUESTIONNAIRE

PLEASE READ EACH OF THE FOLLOWING STATEMENTS, AND THEN CIRCLE ONE OF THE NUMBERS ON EACH LINE TO INDICATE WHETHER THE STATEMENT IS TRUE OR FALSE FOR YOU.

THERE ARE NO RIGHT OR WRONG ANSWERS.

- If a statement is definitely true for you, circle 5.
 If it is mostly true for you, circle 4.
 If you don't know whether it is true or false, circle 3.
 If it mostly false for you, circle 2.
 If it is definitely false for you, circle 1.

SOME OF THE STATEMENTS MAY LOOK OR SEEM LIKE OTHERS. BUT EACH STATEMENT IS DIFFERENT, AND SHOULD BE RATED BY ITSELF. PLEASE RESPOND TO ALL ITEMS.

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
1. According to the doctors I've seen, my health is now excellent.	5	4	3	2	1
2. I try to avoid letting illness interfere with my life.	5	4	3	2	1
3. I seem to get sick a little easier than other people.	5	4	3	2	1
4. I feel better now than I ever have before.	5	4	3	2	1
5. I will probably be sick a lot in the future.	5	4	3	2	1
6. I never worry about my health.	5	4	3	2	1
7. Most people get sick a little easier than I do.	5	4	3	2	1
8. I don't like to go to the doctor.	5	4	3	2	1
9. I am somewhat ill.	5	4	3	2	1
10. In the future, I expect to have better health than other people I know.	5	4	3	2	1
11. I was so sick once I thought I might die.	5	4	3	2	1
12. I'm not as healthy now as I used to be.	5	4	3	2	1

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
					57
13. I worry about my health more than other people worry about their health.	5	4	3	2	1
14. When I'm sick, I try to just keep going as usual.	5	4	3	2	1
15. My body seems to resist illness very well.	5	4	3	2	1
16. Getting sick once in a while is a part of my life.	5	4	3	2	1
17. I'm as healthy as anybody I know.	5	4	3	2	1
18. I think my health will be worse in the future than it is now.	5	4	3	2	1
19. I've never had an illness that lasted a long period of time.	5	4	3	2	1
20. Others seem more concerned about their health than I am about mine.	5	4	3	2	1
21. When I'm sick, I try to keep it to myself.	5	4	3	2	1
22. My health is excellent.	5	4	3	2	1
23. I expect to have a very healthy life.	5	4	3	2	1
24. My health is a concern in my life.	5	4	3	2	1
25. I accept that sometimes I'm just going to be sick.	5	4	3	2	1
26. I have been feeling bad lately.	5	4	3	2	1
27. It doesn't bother me to go to a doctor.	5	4	3	2	1
28. I have never been seriously ill.	5	4	3	2	1
29. When there is something going around, I usually catch it.	5	4	3	2	1
30. Doctors say that I am now in poor health.	5	4	3	2	1
31. When I think I am getting sick, I fight it.	5	4	3	2	1
32. I feel about as good now as I ever have.	5	4	3	2	1

Appendix D
Demographic Data Collection Tool

Appendix D

Demographic Data Collection Tool

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